Futility – Medical and Otherwise

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General Observations

• Difficulty accepting futility and death
• Use of hospice is under penetrated
• Futility can be over and under applied
• Difficult to define beyond “medical futility”
• Application is patient specific
• May apply simultaneously to both chronic and acute conditions
• Quality of life arguments play a dubious role
• Fluid process - many moving parts and the decision may change
I’m afraid there’s really very little I can do…

When is enough enough?
Case 1

- 75yo M in relative good health
- AA → bilateral rib fxr, pneumohemothorax, closed head injury
- ? Capacity → IV narcotics, concussion, hypoxemia, agitation
- Needs intubation...now...pt refuses
- HCD → “no ventilator”
- Family → ”he doesn’t mean it”
- ? Futility → WH at patients insistence
- Controversy → intubate or let die
Case 2

- 38yo F ES lung disease, trach with chronic vent support, on transplant list, wasting
- Repeat hospitalizations for recurrent pneumonia and resp deterioration—always responds to Rx
- Presently in ICU…again…but recovering
- Wants to be taken of vent (no HCD)
- Husband and children at her side, supportive though distraught
- ? Futility → WD at patient’s insistence
- Controversy → continue support or let die
The conundrum...

- Truly *informed* refusal - Is the patient refusing what is being offered?
- Achieving the “medical good”- Is there a legitimate claim for *professional autonomy*?
- Reversible conditions vs. irreversible conditions and inevitable death
- Hope and fear of abandonment at the EOL
- Patients often change their mind at the EOL
- May not be much time to make a decision
The result...

- Frequent lack of clarity
- Moral discomfort
- Fear of reprisal
- The risk:
  - Delay actions that might lead to death…
  - Withdraw or withhold prematurely…
How Does the Current Health Care System Do in Caring for Dying People?

National survey of 1,002 adults conducted by Lake-Snell-Perry Associates for Last Acts, 2002

Excellent 3%
Very Good 8%
Good 24%
Only Fair 33%
Poor 26%
Could not answer 7%
Diagnosis

Symptom-oriented
Patient-focused Treatment

Disease-oriented
Treatment

Hospice

Death

Integration of Palliative and Disease-oriented Treatment in the Trajectory of Death

Abraham, J. Update in Palliative Medicine and End of Life Care
Under penetration of Hospice

• **60% of deaths occur in a hospital.**
  – Most with chronic conditions
  – **74% of these occur after decisions to forgo life sustaining treatment.**

  *Block, JAMA. 2001*

• **85% of patients with cancer admitted to an ICU die there.**

  *Dowdy, Crit Care Med. 1998*
Conflict in End of Life Care

- Defining the patient’s “good”
- Determining prognosis—acute and chronic
- Defining futility
- Different philosophical/religious beliefs
- Cultural/ethnic differences
- Physician's multiple roles
- Defining “quality of life”
- Economic, legal, and ethical concerns
- Knowing who decides
Prognosis

- 20% accurate within 33% survival time
- 63% overoptimistic
- 17% underestimated
- Accuracy decreased as the duration of Dr-Pt relationship increased

Christakis N and Lamont E. *BMJ*. 2000;320:469-472
Ethical and Legal Climate

• **Provider v Patient before 1970**
  - Generally recognized role of providers to act unilaterally for the patient (paternalism model)
  - Patient and family followed “orders”
  - Limited treatment choices
  - Patients usually died at home

• **Patient v Provider today**
  - Courts generally do not recognize the right to act unilaterally unless it’s an emergency
  - Courts generally protect the patient’s right to choose or refuse treatment
Hope, Expectation, and Communication

- Scientific promise
- Faith (“the choice is not ours to make”)
- Professional training (“death=enemy”)
- Medical marketing (“staff for life”)
- Theatre (code blue = resuscitation)
- Family demands (guilt and fear)
- Legal threat
- Professional score cards (P4P)
- How Dx and Px are communicated
- Changing relationships (Doc for the day)
Choice of CPR in the elderly

• How it’s presented: [Fagerlin, 2004]
  – 12% if phrased negatively
  – 18% if phrased in HCD already in use
  – 30% if phrased positively
  – 75% changed their mind at least once when presented differently

• Influence of knowing prognosis
  – 41% before, 22% after [Murphy, 1994, NEJM]
Hospice Referral

- Eligibility:
  - “Terminal” condition
  - Life expectancy 6 months or less
  - No further “curative” or life prolonging Tx
  - Caregiver
  - Medicare Part A
    - 90% hospices in U.S. certified by MC
    - Part A available to 80% of those eligible
Who Uses Hospice

• Cancer > 50%

• Heart, lung, HIV/AIDS, renal, neurodegenerative (ALS, CVA, dementia)
  – “failure to thrive”

• Other “incurable” conditions: ? anorexia nervosa?
Barriers to Hospice

- Fear of abandonment
  - not ready, or afraid, to “give up”
- The “treat” mentality by physicians
- Prognostic inaccuracy—”terminality”
- Slow decline – Dx not “fatal” (elderly)
- Lack of a caregiver
- Lack of financial means
- Racial and cultural disparity (82% white)
- Religious belief (sanctity of life)
- Access (inner city, rural)
Futility

- Can it be defined?
- Who defines it?
- Once determined is it irrefutable?
- Does this concept even pertain anymore?
Medical Futility

- *Futilis-e* *(Oxford Latin Dictionary)*
  - of vessels: fragile
  - of things: vain, pointless
  - of persons: ineffective

*(Desired or intended outcome highly unlikely)*
Futility

- Oldest criterion in traditional medicine
  - Hippocrates: Treatise on Medicine (ca 400 BC)
- Unrecognized in modern medicine before 1987
- 134 articles in 1995
- 31 articles in 1999
- The struggle
  - Defining it…
  - Autonomy of patients v autonomy of doctors
  - Dispute resolution
- No agreement about underlying principles by medical community
FUTILITY

Proportionality Relationship:

\[ F \rightarrow \text{Effectiveness} + \text{Benefits} \]
\[ \text{Burdens} \]

(Not a mathematical equation)

Physician determines “Effectiveness”:

A measurable changes in natural history of disease or symptoms can be reasonably expected.

(…reasonable medical certainty of intended outcome)

Patient and Physician determine “Benefit” together

Patient determines “Burden”: cost of treatment
Futility

- Proportional assessment (effectiveness, benefit, burden)
- Made by the providers (team) the patient, the family, and others
- Fluid calculus toward a defined goal
- Accounts for new and changing variables
- Goal = “good” of the patient
When does the obligation to treat no longer exist?

Obligation to treat

Ineffective

Effective

Burden

Benefit
“Futility” in Hospice

• Is disease treatment in hospice morally justified?

• Palliative vs. therapeutic
  – compatible with “allowing a comfortable death”

• Futility may pertain to the underlying disease but not the acute condition

• Treatment Goals in Hospice: That which is reasonably “effective”, “beneficial”, and not unduly “burdensome” short of CPR or other life sustaining interventions
Let’s vote…

- Intubate vs. not intubate in Case 1
- Ventilate vs. not ventilate in case 2
Case 1

- Anesthesiologist refused to intubate
- Trauma surgeon intubated with promise to WD if long term vent dependency occurred
- Claim of futility did not pertain:
  - not terminal
  - treatable condition
  - patient refusing what was not being offered (fear of vent dependency vs. bridge to recovery)
  - questionable capacity and unsure of what patient “might want” (per family)
- “Rule of rescue” — clinical judgment to preserve life when unsure of patient’s preferences in the face of an acute, life threatening, and treatable condition
- Pt came off vent p 3 days and said, “thank you”
Case 2

- Considerable moral discomfort by the team—effective treatment yet respecting patient’s right of refusal and her dignity

- Claim of futility supported:
  - burden>benefit (per patient)
  - pt refused what was being offered
  - capacity not questioned due to consistency of statements
  - terminality of condition

- Pt much relieved, relaxed and happy to have regained her dignity—”someone finally listed...thank you...”

- Ventilator was removed and patient died 30 min later while receiving palliative sedation
Opportunities for Change

- Training and education—team concept
- Encourage dialogue about cases—utilize ethics and palliative care consultation services
- Encourage hospital policy that promotes and automates *early* palliative care and hospice referral
- Advocate for health policy reform
  - OH DNR—success!
  - Clarify and enhance eligibility criteria for hospice
  - Improve reimbursement
- Promote cultural awareness and health literacy
- Promote social awareness
Summary

• Futility (or nonfutility) can be a legitimate ethical claim beyond whether or not treatment is effective.

• Futility calculus is relevant to both chronic and acute conditions (effectiveness, benefit, burden).

• Hope and obligations of non abandonment are important ingredients of palliation.

• Palliative and interventional treatment can coexist when acute, chronic, and terminal conditions coexist.

• The narrative of relationships is crucial to the effective application of futility.
Thank you!